

BREAKING GROUND

SPECIAL ISSUE



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Cover Photo: Michael Weininger (left) and Mike Murphy

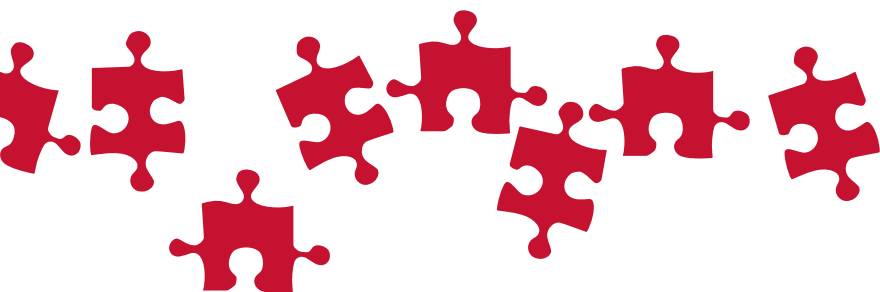
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EDITOR'S NOTE

Autism is much in the news these days. Books and movies about people who have an autism spectrum disorder (ASD) seem to appear with a certain regularity. In January, Claire Danes received a Golden Globe Award for her portrayal of the renowned Temple Grandin, who embraced the actress warmly upon the announcement.

Also in January, U.S. Representatives Mike Doyle, of Pennsylvania, and Chris Smith, of New Jersey, released a report describing autism-related research and service activities carried out by the U.S. Government over the last four years. This report, which was required by the Combating Autism Act (CAA) of 2006, describes action that the Federal Government has undertaken since enactment of the CAA—primarily in the fields of research and services. The report was prepared by the Office of Autism Research Coordination, National Institutes of Health, Department of Health and Human Services.

As an introduction to the *Breaking Ground* Special Issue on Autism, we reprint the conclusion of the report. We hope the articles that follow will inform, educate and motivate our readers. A copy of the full report is available on the Internet at <http://doyle.house.gov/autism.shtml>, then type Report to Congress in the search box

Report to Congress on Activities Related to Autism Spectrum Disorders and Other Developmental Disabilities Under the Combating Autism Act of 2006 (FY 2006-FY 2009)

CONCLUSION

In the past four years under the provisions of the CAA, significant advances have been made in our understanding of ASDs. Notably, reliable estimates of the prevalence of ASDs and a clearer picture of both the opportunities and gaps that exist in ASD research and services are now available. With substantial Federal support, researchers continue the crucial task of evaluating interventions that provide lasting, meaningful benefit to people with ASDs. Large-scale efforts in data collection, consolidation, and sharing are empowering researchers and health practitioners with knowledge not available only a few years ago. With increasing phenotypic

and biological knowledge, medical practitioners are beginning to classify sub-categories of the wide spectrum of autistic disorders, which will be crucial in future efforts to provide individually tailored interventions. Within the biomedical research community, there is optimism that a continued rigorous focus on identifying genetic and environmental triggers to ASDs will yield innovative treatment and prevention strategies.

Through intensive surveillance and research efforts, researchers and Federal agencies can also better identify the unmet societal needs surrounding ASDs. While the median age for ASD diagnosis (~4.5 years of age) appears to be favorably on the decline, CDC [Centers for Disease Control and Prevention] data indicates a critical need for improved access to early evaluation and diagnostic services. The typical time gap from developmental concern to diagnosis is over 2 years. With a continued focus on ASD awareness and training, within both the public and healthcare spheres, this critical time gap can be lessened. Increased attention is being given to pinpointing underserved communities where diagnostic and intervention support is in the greatest need. Strategic efforts aimed at underserved populations are under way to encourage ASD awareness, early diagnosis, and intervention, but additional efforts will be needed to provide the necessary evidence base to support a wide variety of new interventions and services and supports to provide for the needs of people on the autism spectrum. In addition, services and supports programs across several Federal agencies are actively identifying best practices and implementing programs to increase quality of life for people with ASD across the lifespan. Finally, the Federal coordination provided by the Interagency Autism Coordinating Committee (IACC), has successfully identified key research and services priorities and has fostered enhanced communication and collaboration between Federal agencies, private foundation partners and the public. This Federal coordination will continue to be needed to monitor progress, provide a forum for public input into Federal ASD policy, and help agencies bring critical research into practice in the form of effective programs to help people with ASD and their families.

AUTISM AWARENESS MEETS PIZZA ART

BY MICHAEL WEININGER

I think once you know someone with autism and you see a sign with 'autism awareness' on it, you think of him or her. At least that's how I am. Often, when I'm driving and I see one of those autism awareness ribbon magnets on a car, I wonder if people are getting the message. Are they learning about autism?

So...how to do more than just bring awareness to autism? How do we educate people about different aspects of autism: what it is, what it means, and what individuals with autism are like, capable of and interested in?

Let me start by explaining how I combined two vastly different establishments that I frequent. The first one is Norris Academy, a division of Camelot Schools located in Norris, Tennessee, where I serve the population that inspired my questions. Students there have different disabilities, including autism. The interesting thing for me is, at times, I'm not even sure which student has autism, since autism has so many different aspects and faces. I teach art at Camelot at their campuses in Norris and in Kingston on the weekends, along with my regular art teaching job at Bearden Middle School in Knoxville.

As I teach at different schools, working with students with different ages, abilities and needs, I sometimes borrow and share lessons with myself. I notice there might be no evidence of differences between students' intellectual capacities concerning the comprehension of my lessons, but quite a bit of difference in their creative intensity or level of interest. In other words, autism does not have to affect an individual's artistic skills or enthusiasm for the subject.

Through my experiences teaching art, I also have learned that showing off my students' accomplishments can be very encouraging to them. One place I enjoy displaying student work happens to be one of my favorite places to eat in the area: DaVinci's Pizzeria & Calzones at 3337 Sutherland Avenue in Knoxville. I am on good terms with managing partner/pizza baker, Bob Sircy, who, besides making delicious Italian cuisine, has a terrific sense of community involvement and is constantly open to ideas for art showings at his place. It was time for our pizza/art show to change and this time he approached me with an idea of a medium to use: surplus pizza boxes. The wheels started turning and the concept of collaborating with students at Norris Academy came to me.

Before I go any further, I want to say how truly incredible the Camelot program is. Camelot has a motto, "Believe, Trust, Achieve". Though that motto can be witnessed daily on their campuses as they work with students, I believe this philosophy helped us accomplish this particular event. It was made possible



through lots of teamwork, ranging from executive director Chris Frierson, therapist Jill Lumpkins, director of human services Charlee Villeneuve, senior counselor Mike Murphy and residential counselors Levi Mullins and Brandon Stansberry.

I remember clearly the evening when I first mentioned the pizza box art idea to Mike and Levi. There was a computer in the room and instantly the two began brainstorming ways that we could complete the project. Since I only teach at Norris once a week, it was decided that I would bring the pizza boxes to campus and the Camelot staff would take the project from there.

That's exactly what happened. Basically, a template and structure was constructed for an "autism awareness" puzzle symbol enlarged on multiple pizza boxes. The vision included student art displayed on the boxes, with applicable terms on each of the sections, words that could contribute to peoples' understanding of autism. We also decided to include definitions of the terms displayed, along with additional and related information supplied by Jill and Charlee. We ultimately turned this information into the art show invitations, that DaVinci's was gracious enough to have printed professionally, to give out and display around the pizzeria.

Once the invitations and pizza box art project were completed, openings were scheduled. A private opening was set for just a handful of the student artists, who came to DaVinci's for an amazing dining experience, including custom pizzas for students with special dietary issues. The students glowed with pride when they saw their work displayed.

For the official opening, we invited members of the local media. The show ran for a couple of weeks and we had wonderful feedback from the customers. Bob Sircy and co-worker/pizza baker/Pellissippi College student, Steve Rogers, related several stories from their customers that were extremely moving. One customer said that his mother was raising another child who could possibly have autism, and he was going to share the information presented at the show with her. For me, that made the show and its concept of autism awareness a true success.

Michael Weininger is an art teacher in East Tennessee.

A SISTER'S PERSPECTIVE

BY EMMA SHOUSE

One of the most important roles in my life is being a sister. I have two younger 15-year-old brothers who are twins, Evan and Brendan. Evan has autism. He does not verbally communicate very well, but is constantly surprising my family and those around him with how bright and observant he is.

It is hard to explain all the ways that having a brother with autism has shaped my life. Evan was diagnosed when I was about eight years old and it is sometimes difficult to remember a time when autism wasn't a reality of my family's life.

My relationship with Evan is simultaneously one of the simplest and most complicated relationships in my life. It is beautifully simple because there is never any true anger, resentment or pain between us—only unconditional love. Evan understands much more than most people give him credit for, but even so, he has no knowledge of how to be cruel or petty. It doesn't matter what else happened in my day, being with Evan can cheer me up. My relationships with the other members of my family have changed quite a bit since I moved out to go to college and have grown into my own person over the past couple of years, but my relationship with Evan is constant, simple and reassuring in the most important of ways.

I have faith that, on a certain level, we will always understand each other and be able to have a connection that doesn't need to be expressed through words. This is something I don't think many people without a loved one with a significant disability can truly understand.

Being a sister to Evan is also one of the most complicated things in my life. It is complicated because there seems to always be a need for explanation when telling people about my family for the first time. People want to know why I must sometimes be available to provide childcare for a brother who is 15. Upon their finding out that he has autism, the floodgates open to more personal questions about his level of functioning, communication, behavior problems, my feelings about his autism—questions that seem to always come with the introduction of disability into a conversation. It was complicated growing up and wanting to have friends over to the house, and trying to explain why they shouldn't be too bothered when (not if) my younger brother burst into the room and wandered around for a while. I never really knew how to cope with being frustrated or angry when my things were routinely destroyed, when I was awakened at the crack of dawn on weekends when I would try to sleep in, when my family could only go to restaurants where Evan liked the food and on and on. How can you be upset at someone without any bad intentions and yet who still can cause such havoc in your life?

It is difficult to explain to most other people why staying close to home for college and likely living near my family for the rest of my life is not sacrificing or settling for something less than what I want. Being a good sister to Evan is part of who I want to be and I would be letting myself down, if I abandoned that value. My relationship with Evan is

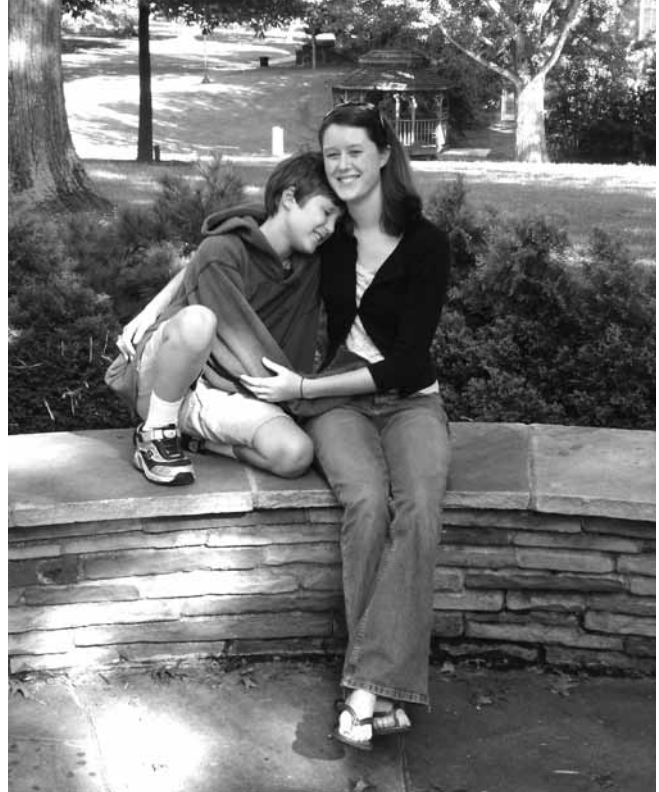


Photo by John Shouse

Evan (left) and Emma Shouse

complicated because I constantly wonder what will happen to Evan in the future. What will his life be like, and what will my role be? How much do I let being the sister of a brother with autism determine my own future? I wonder if he will ever learn to communicate verbally. I wonder whether he knows what he wants for his future and, if so, if he will ever be able to express that.

Having a sibling with autism has taught me compassion, patience and an appreciation for others' differences. It has made me realize you should never be too quick to judge someone, because things are not always as they seem. A little boy having a tantrum in the supermarket may not be a result of bad parenting, a girl who falls asleep in her high school class may have been kept awake all night by her little brother, or a parent who snaps at you may be dealing with more than you could ever know.

Having a sibling with autism has taught me that one of the most rewarding and powerful feelings you can experience is feeling like you have helped someone in an important way. It is a major factor that has propelled me toward the career of social work because I want to be able to help people change their lives for the better. Having Evan in our family is a constant challenge and blessing all at the same time, and continually makes us stronger and better together. My greatest wish for Evan is that no matter what his future holds, he will be as happy as possible and will always be surrounded by people who are dedicated to helping him realize his full potential.

Emma Shouse is a student at Belmont University and completed a Public Policy internship with the Council on Developmental Disabilities in August 2010.

If you have a sibling with a disability and would like to make contact with other brothers and sisters, an opportunity is available through Tennessee Adult Brothers and Sisters (TABS). On April 8-9, 2011, TABS will host the Third Annual

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Tennessee Brothers and Sisters Conference at the Holiday Inn Vanderbilt in Nashville. At the conference, you will hear featured Keynote Speakers:

Don Meyer - *Director, Sibling Support Project*
Dee Dee Eberle - *Director, Chapter Excellence at The Arc of the US. Conference*

Sessions will include:

- The Sibling Leadership Network
- SibShops
- Advocacy 101
- Know Your TennCare Rights!

- Inclusion in Faith Communities: Information on Efforts in Tennessee
- Supporting our Brothers and Sisters Using Person Centered Thinking and Planning Tools
- Siblings of Children and Adolescents: Involvement, Caregiving and Planning for the future.

Plus you will have the chance to meet and talk with other brothers and sisters.

For more information, visit kc.vanderbilt.edu/tabs or contact Ashley Coulter at 615-343-0545 or ashley.coulter@vanderbilt.edu.

AUTISM ORIENTATIONS BECOME STATEWIDE INITIATIVE

BY AMANDA PELTZ & JOHN SHOUSE

When individuals and families affected by

autism are first learning about the disorder, nothing can replace the benefit of a personal encounter with knowledgeable professionals and parents. Many families of children with autism spectrum disorders (ASD), particularly those living in rural areas, may feel isolated and disenfranchised by not knowing other families affected by autism.

Connecting with others in the autism community to hear their successful parenting tips or empathize with them about the stress of parenting a child with an ASD goes a long way toward reducing this isolation. For over a decade, the Autism Society of Middle Tennessee (ASMT) has been providing Autism Orientations as a way of initiating community connections while also fulfilling a basic need for introductory information on autism spectrum disorders.

Autism Orientations are two-hour informational sessions about autism spectrum disorders that are conducted by a professional specializing in ASD and a parent of a child with autism. The specialist provides an overview of the characteristics of autism spectrum disorders, how behavior is affected, implications for learning, and common therapies and interventions. The parent provides a more personal perspective on intervention and the family support services available in our community. In addition, they discuss parenting choices that may lead to more positive outcomes for the child and family, benefits of connecting with the autism community, and successful strategies for working with teachers, therapists and other professionals. These events are intended not only for parents of newly diagnosed children, but also for newly diagnosed adults, grandparents, caregivers, educators, therapists, psychologists, pediatricians and other medical professionals, and other interested community members.

ASMT has been hosting these free, bi-monthly Orientations primarily in Nashville, and has presented them in other areas of Middle Tennessee as funding has been available. In traveling to rural areas of the State, ASMT has seen first hand that information on research-based therapies, as well as federal, state and local non-profit agencies that serve this population, currently are available only in the major urban areas. Because of this, many families may not understand the possible long-term consequences of delays in their child's development as well as their decisions regarding interventions. This lack of understanding can lead to inconsistent

implementation of educational programs and therapeutic interventions. In the case of autism, it is also likely to lead a family to focus on information about interventions from less reputable sources, diluting the family's focus during a critical time. These families also may not realize their own need to learn about available supports, advocacy skills and setting high expectations. Poor skills in these areas may increase the likelihood of poor outcomes for their children with autism. They may feel frustrated or helpless by their limited awareness of the supports available to them. Rural settings can exacerbate these feelings and increase stress on families.

In order to address this need and to empower these families, ASMT has partnered with the Tennessee Early Intervention System (TEIS), the Autism Society of East Tennessee (ASET) and the Autism Society of the Mid-South (ASMS) to produce 27 Autism Orientations across the State of Tennessee between August 2010 and September 2011, providing a single, unified message with resource information tailored to each community. These events are funded by the State of Tennessee, Department of Education, through the American Recovery and Reinvestment Act funds. By holding at least three orientations in each of the nine TEIS regions, these organizations believe they can hold at least one orientation well within one-hour's driving distance for anyone in Tennessee.

Regional Coordinators in each of the three major areas of the State are calling on local service agencies, support groups, school systems and community leaders to make these events successful. Whenever possible, local specialists and parents are trained to present the orientation, in an effort to build the capacity of the local community to continue to provide this training past the grant period.

With the prevalence of autism spectrum disorders at an incredible 1 in 110, autism is having a significant impact on our society. ASMT has found that the orientation sessions provide guidance and direction, connections to community supports, exposure to intervention options, and ultimately sets the foundation for positive outcomes for individuals with an ASD.

Amanda Peltz is executive director of the Autism Society of Middle Tennessee.

John Shouse is the father of a child on the autism spectrum, past president of ASMT and a Partners in Policymaking™ Leadership Institute graduate (2002-03).

LAUGHING, CRYING

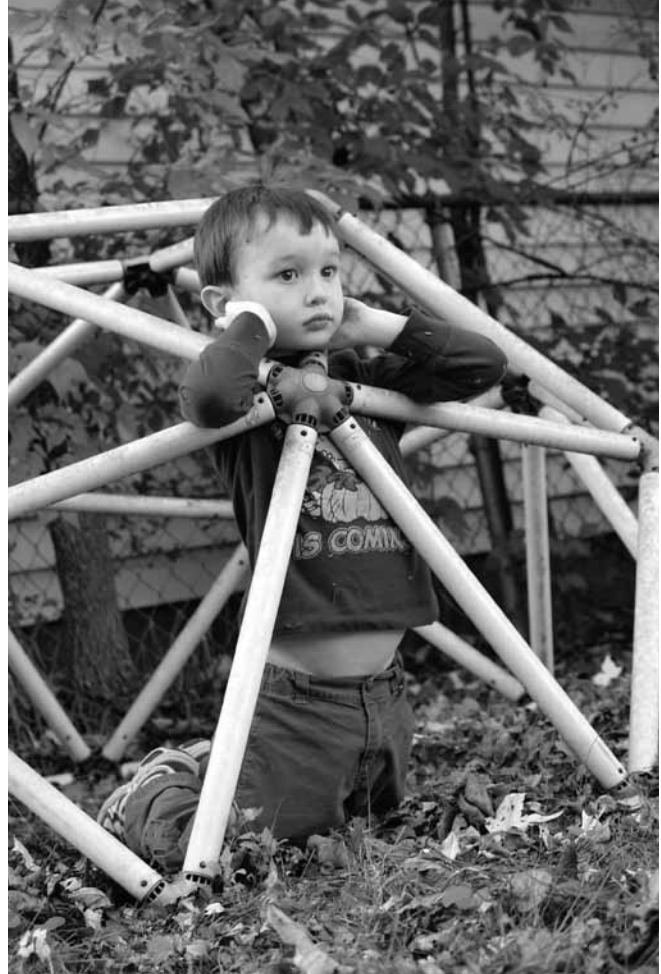
When my parents received word they'd been chosen as the parents of my younger brother—both he and I are adopted, from different biological parents—I remember clearly my mother and father standing in the living room of our home in North Augusta, South Carolina, my mother crying deeply. When I asked why, she told me, "People don't just cry when they're sad. They can cry when they're happy too."

My young five-year-old mind turned this puzzle over and over at the time, though of course I've had more than a few instances in the 35 years since in which I have personally experienced that paradox. However, only when my parents and I stood about to enter the hospital room where our son, Rohan, and his biological mother waited did I have occasion to feel the full impact of a moment filled with such overwhelming joy and simultaneous tears.

Little did we know, then, just how many more of such moments lay ahead. What was it about the echo-y hallway where we lived during his first year and a half that made Rohan so afraid, terrified even? Why didn't he roll his trucks across the floor, but instead lay beside them, wheel-side up, spinning them over and over and over again? Being first time parents, we had no real sense of what "typical"—or, for that matter, what "atypical"—looked like. I'm not entirely sure we do even now. Still, our pediatrician helped us look at how Rohan engaged with the world through eyes that had seen many children as they grew and developed, each of whom had their own place along that typical/atypical spectrum. With that helpful perspective, it became clear that Rohan was—is—somewhere along the autism spectrum.

Still, my wife Kate and I were tough sells. We both hesitated to buy into a diagnosis that seemed like just a way to tie a bunch of disparate concerns into a tidy package of symptoms, especially when that package could have such long-range implications for how others would see and understand our amazing little boy. As we have lived into this diagnosis, though, this remains our struggle, as much with ourselves as with others. We celebrate each time Rohan brings us a photo of a box of Graham Crackers, successfully telling us what he wants to eat; we laugh, despite ourselves, when we walk around the corner to see each and every one of his Muppets lined up on the floor; and we cry for Rohan, and for ourselves, each time he becomes so overwhelmed, so frustrated, so fear-filled, that he bangs his head repeatedly on the wall or floor or counter. While infrequent, deepening our dual sorrow is that desperate scream, one that really can only be described as the scream of a terrified animal caught, not in a trap, but in a world whose order and reliability can fall apart without warning.

Through all such moments, we remain Rohan's proud and happy parents. How, I am sometimes not exactly sure. When I'm the closest to putting my finger on it, I am directed repeatedly to the creative,



Photos by R.E. Johnson, Jr.

Rohan Johnson



Left to right: Kate, Rohan and Dahron Johnson

regenerative, power that living in such a paradox of joy and fear, heartache and happiness, crying and laughing, seems to mysteriously and constantly provide. I'm not the only one, of course, to muse on this.

I've never stopped being a fan of good children's books and, no surprise, there are a couple that sum up the situation quite nicely. The title of Jules Feiffer's *A Barrel of Laughs, A Vale of Tears* says it all when it comes to describing our day-to-day experience. However, it is Norton Juster's quietly beautiful *The Hello, Goodbye Window* that captures the "why" so tellingly. As the young narrator says simply, "You can be happy and sad at the same time, you know. It just happens that way sometimes." And, constantly reminded and relearning the power of this "it just happens" paradox, so it goes with us.

STUDYING AUTISM SERVICES IN TENNESSEE

BY JOSEPH WOODSON

Over the past decade, the number of children in Tennessee schools receiving special education for autism has more than tripled. That said, what do we really know about autism in Tennessee? What is the prevalence of children with autism in our State? How do school systems serve this student population? For what reasons do parents and caregivers contact their State legislators to report dissatisfaction with school-related autism services? These questions are what led the Comptroller of the Treasury's Offices of Research and Education Accountability (OREA) to begin studying autism services in Tennessee.

Why is the Comptroller's Office studying autism?

OREA was created by the State legislature in the early 1990s to serve as an unbiased public policy think-tank for State legislators and the public. OREA studies are based on detailed research and analysis of available literature, as well as extensive interviews with various stakeholders across the State. OREA does not make recommendations, but rather aims to inform State legislators on important findings concerning public policy issues.

State Senators Randy McNally and Jamie Woodson asked OREA to study autism after receiving constituent complaints about educational services for children with autism. OREA is releasing the results of its autism study in a three-part series. Part 1 – An Introduction to Issues and Data Collection Methods was released in 2009. Part 2 – Education was released in December 2010. Part 3 will cover healthcare services, and is scheduled for release in 2011. All OREA reports are available online at <http://www.comptroller1.state.tn.us/orea/>.

What have the Comptroller's studies found?

The studies include three general observations that any policymaker should bear in mind when considering autism services. First, the needs of each child with autism are unique and educational interventions must be individualized. Second, policies concerning autism services affect all children with developmental disabilities. Third, best practices for working with children with autism are largely in development, and Tennessee and the nation are still learning how best to provide needed services.

Specific study findings include:

The number of children being diagnosed with autism is growing rapidly, but State officials don't know why. The number of children and youth receiving autism-related special education services in Tennessee more than tripled between 2001 and 2007, rising from approximately 1,293 students to 4,019 students. However, it is not known whether those numbers have risen because of an increased

prevalence of autism or because autism is being identified and diagnosed more frequently.

Statewide coordination of the numerous agencies providing services is lacking. Currently, there are at least six separate State agencies and many organizations at the regional, district and local levels that provide or administer autism resources and services. It is difficult to obtain accurate, reliable information on who receives autism-related services, which services they receive, and where those services are available because data and records are not coordinated and collected at the State level.

Some states have autism registries. Although operating registries for a few other medical conditions, Tennessee does not have an autism registry. Over the past decade, states such as Delaware, New Hampshire, New Jersey, Utah and West Virginia have created autism registries to evaluate services and inform constituents of services available to them. An autism registry for Tennessee, similar to those already existing in the State for medical conditions such as traumatic brain injuries, birth defects and cancer, could provide specific information about statewide capacity for providing autism services.

Educational and early intervention services are complicated and can be difficult to navigate for children with autism and their parents. Children and youth with autism transition into and out of a number of different services over the course of their early childhood and elementary and secondary education. These transitions are often a challenge for children with autism and their parents because eligibility criteria and the extent of services vary among special education program categories. Additionally, methodologies for educating children with autism are largely in development. This can result in disagreement between parents and school officials concerning treatment methodologies and the amount of time a child should spend in the regular classroom.

Tennessee does not collect information on the methods of training and supports used in local school systems. School systems are responsible for providing K-12 teachers with training on how to teach students with autism. However, each system provides this training differently, and the State lacks comprehensive data on which school systems' teachers are most prepared to work with autism. Some teachers may receive training through the Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) at the Vanderbilt Kennedy Center. Other school systems, like Knox and Williamson County Schools, provide in-house training and support for teachers.

State and local educational agencies work collaboratively with higher education institutions for teacher training and preparation. Schools

of education at Tennessee's public higher education institutions plan to increase the amount of autism-specific coursework in their curriculums, according to a 2009 OREA survey.

Other states are taking notable steps toward improving autism services. States like Alabama and Pennsylvania have developed task forces or state-level agencies for autism services, while states like Florida and North Carolina have implemented comprehensive systems for teacher training and other support services. A 2002 study of autism services in Tennessee recommended a statewide autism support model. The proposed model includes an education component, with eight regional autism support teams. Each team would include a

special education teacher, a speech and language therapist, and a behavior interventionist; teams would receive continuous training and support from TRIAD.

For additional information about the series or a more detailed explanation of these findings, please visit the OREA Web site <http://www.comptroller1.state.tn.us/orea/> or contact Joseph Woodson by phone at 615-401-7874 or e-mail at Joseph.Woodson@tn.gov.

Joseph Woodson is associate legislative research analyst for the Comptroller of the Treasury.

COMING TO TERMS WITH ASPERGER'S



BY WILLIAM N. BENSON, JR.

Until I was 13, I never knew I had an autism spectrum disorder. I was diagnosed with Asperger's Syndrome in the middle of 8th grade. Throughout my pre-middle school life, I struggled with many social and emotional issues. I had trouble making friends and being included.

Frequent bullying was the norm. Anger and frustration

became overwhelming at times. The various experts my parents took me to only seemed to help with parts of whatever was going on, never the big picture. The diagnosis came as quite a relief to both my parents and me; we finally knew what was happening and could begin to deal with it.

Finding the right fit for high school was the first challenge. My parents investigated every high school in my hometown. Then we began considering different homeschooling options, which included on-line high school programs. My parents looked at several on-line schools before they found the Florida Virtual School. It has worked very well for me and I intend to finish high school with their program. On-line schooling has had many advantages. Without all the distractions of a typical classroom (the noise, flickering lights, uncomfortable chairs, smells, etc.), my focus is on learning, which I enjoy. I am less frustrated and agitated after a school day at home as opposed to a day spent in a general school environment. However, three years into homeschooling, I realize I miss the sense of identity that comes with a traditional school. The "home school" label at times exacerbates my feeling of isolation and seems to highlight my differences. The question, "Where do you go to school?" makes me self-conscious.

Sorting out my own behaviors and responses as well as learning how to decipher those of others has been another major emphasis.

Working with a counselor and joining a social skills group have been key factors in successfully navigating interpersonal communication. At times, I want to do what I think "normal" teenagers do—like hang out with friends. Though I understand people a little better, I still don't think the way others my age do. I don't share similar interests, so I am often disappointed by group activities, even though I wanted to participate. Being with people can still be difficult and tedious. Sometimes it's just too much work and I don't feel like it. But I know how far I've come and that is encouraging.

Becoming involved in the autism community has been rewarding. It has provided support and encouragement, as well as the opportunity to help others by sharing my own experiences. In April 2010, I participated in the Autism Awareness 5k and placed second in my age group (15-16). Later in the month (April being Autism Awareness Month), I wrote an exercise book aimed at promoting fitness for all levels of ability. I was fortunate to be recognized for my project and invited to participate in the Regional Autism Advisory Council's 2010 Conference "Whole Body, Whole Life" in Cincinnati, Ohio. I also was asked to present my book and share my fitness journey at the Ohio Parks and Recreation Association's Annual Convention in February 2011.

In the security of autism conferences and local Autism Society meetings, I am comfortable being myself. In the safety net of this community, I have begun to come to terms with and take ownership of my Asperger's Syndrome. With increasing self-acceptance, I am on to the next goal of self-advocacy. Being able to recognize and request the accommodations needed is one of the most critical life skills for me to learn.

Despite my successes so far, I'm still concerned about taking on life by myself. I don't feel very sure in my ability to deal with the burden of everyday life on my own. College is also a big issue; after four years of learning at home, will I be able to keep up? Will things really be easier like everybody always says? Or will it just be a repeat of middle school?

BELINDA MARTINEZ

Provides Support and Hope for Hispanic Families Living with Autism

BY NED ANDREW SOLOMON

On December 28, 2005, Belinda Martinez arrived in Nashville from Puerto Rico. She had just turned 21, was a single mom with a young son, Drak, with autism—though without an actual diagnosis. “I was reading about autism, and I was looking for the signs, and he had all the characteristics,” said Ms. Martinez. “What brought me here to the States was to look for help for him.”

Ms. Martinez called her sister, Sandra, who lived in the States with her husband, Luiz, and asked for a plane ticket. She had done some research and decided she wanted to land near Vanderbilt, because of the work they were doing with kids with disabilities. “I didn’t really understand what I was reading, because I didn’t have any knowledge in English, but I understood some of the words,” said Ms. Martinez. “I sold my two cars, I left my university and my job, and I came here with two suitcases.”

Once settled, Ms. Martinez wasted little time. She signed up with and began receiving services for her son through the Tennessee Early Intervention System (TEIS). After six months, she was able to schedule a diagnostic appointment at Vanderbilt Children’s Hospital. In Puerto Rico, she was told by professionals that a diagnostic evaluation would not take place for four more years.

Breathing just a bit easier knowing her son was on the right track, she began to address other personal goals. “I had to start learning English; that was the first area where I had to grow,” Ms. Martinez said. “From there this passion—we call ‘don’ in Spanish, it’s like a ‘special gift’—started developing in me to help people. But first I had to help myself. I was going to start learning; start getting more educated.”

She eagerly attended trainings at Vanderbilt and other seminars and conferences, including a particularly inspiring one with Temple Grandin. In 2009, she began spreading what she had learned, and what was working well with her son, to others by creating a Hispanic Family Autism Support Group in Clarksville. “That was the



start of working in the community ‘officially’,” said Ms. Martinez. “I was definitely working already. If I saw a family and I saw the child had the characteristics and I didn’t have a doubt, I was very bold to tell them, ‘you have a problem and you need help’.

“If it was a Hispanic person, I know how to work with the language, the conversation,” continued Ms. Martinez. “If it was an American person, I just take part of any sentence. For example, ‘this child makes me so stressed.’ And I’d say, ‘do you think he might have a disability?’ So go to this place and you can get help.”

Sometimes it was as simple as explaining to a parent what autism means, or which of the child’s attributes or behaviors might point in that direction. Then, if there was some recognition that the child might be on the spectrum, Ms. Martinez was ready and willing to share a file full of available services. “Most of the time I give them my card, and I make appointments for them, and go with them to different resources,” said Ms. Martinez. “And now I keep people educated with seminars and conferences through my support group. And I always follow up to see if they need any help. If a parent or a family needs me, I’m always there 24/7. I never turn off my cell phone.

“I don’t leave them alone, until I see that they can fly,” continued Ms. Martinez. “I worked with one mom for two years. Now she can fly alone. Now she has self-esteem, she is stronger. She can now advocate for her son.”

The support group meets every three months and currently draws about 17 people. She also coordinates workshops where professionals participate, like teachers and therapists and representatives from HeadStart, Department of Education and STEP. “Unfortunately, we don’t have a lot of resources in Clarksville, so when we have something like this people come,” said Ms. Martinez.

In the support group, the majority of her participants are single moms. When it’s a couple, Ms. Martinez works hard to encourage the male to participate. But many of the men in her community

feel strongly that the family can, and should, take care of the situation without outside help, or are simply in denial about the disability itself. "Of course dreams die, but other dreams come from that," said Ms. Martinez. "Hope is something that I can provide now. Hope, and the motivation to try something new. My son learns something new every day—and then we have a party in our house! I try to help people see things in a positive way."

Assisting others through personal conversations and the support group setting, and providing opportunities for professionals to learn about autism has yielded some unanticipated benefits for her son. "Since I've been working with people, I've seen my son's behavior get better," said Ms. Martinez. "Because he saw the love—even if he can't express it himself. He's not able to express himself, but he knows he's part of this. He's a great guy, and has a beautiful heart."

According to Ms. Martinez, Drak, now seven, is doing very well in second grade in a public school in Clarksville. She is quick to credit

working 24/7 with Drak, incorporating strategies she observed during her son's therapy sessions. "I don't leave the professionals to do everything, because they can't!" said Ms. Martinez. "They are there an hour and a half once a week, so most of the other time I work with him. I look for new techniques. And then I share with the team—doctors, therapists, aides, teachers, families—what I have learned."

Besides running the support group and providing whatever help she can to families in the Clarksville area, Ms. Martinez is continuing her education, and working at Vanderbilt on the Parent Stress Intervention Project, where she interviews families who have significant stresses in their lives. "It gives me a chance to develop more skills while I do what I love: helping people!" said Ms. Martinez. "I cannot perceive my life without helping kids and adults with disabilities. This is my world, really. I think I've found what I like to do."

Ned Andrew Solomon is director of Partners in Policymaking Leadership Institute at the Tennessee Council on Developmental Disabilities.

BOOK REVIEW: *Last to Leave Home*

BY ASHLEY COULTER

"Live each day to the fullest. Get the most from each hour, each day, and each age of your life." This is one lesson that Carolyn Baker, author of *Last to Leave Home*, was reminded of on a daily basis by her brother, Mark. Mark was one of her six siblings and happened to have Down syndrome. He loved sunshine, coffee, fishing, swimming, his group home, McDonald's and, most importantly, his family.

In this collection of short stories about various occasions, including Mark's very own graduation and Mark learning to swim, Ms. Baker captures the essence of her family: love. Love for each other, and especially love for Mark. It also captures an important decision her parents made. During the time when doctors recommended sending babies born with disabilities to institutions, Ms. Baker's parents made the decision to keep Mark at home. They knew he would thrive in a family atmosphere. Through these stories, you can see the love and support that the family had from each other and from their local community.

One of the most endearing stories concerns Mark's 50th birthday. The family decided to throw him a big party and invite his entire group home, relatives and friends. The theme was sunshine and fishing—two of Mark's favorite things. They even brought in a local band for dancing! Upon arriving, Mark went around shaking hands and giving hugs to everyone who was there to help him celebrate. At one point during the party, Mark made his way to the microphone. No one knew what to expect, when all of a sudden, a tearful "Thank you" came across. And then he said it again. While most of his speech was hard

to understand, the party-goers could tell, during that magical moment, that Mark loved every minute of having his closest friends and family there with him.

Ms. Baker does a magnificent job of organizing this book. *Last to Leave Home* is separated into three sections that relate to stages of Mark's life. At the beginning and end of each chapter, there is some helpful information for parents and siblings of people with disabilities. This includes tidbits of research, statistics and advice from reliable sources. She also includes a list of resources in the back of this book. Though the audience is vast, parents and adult siblings can most relate to this. *Last to Leave Home* will allow them to know that they are not alone, while also allowing them to learn from the Baker family.

Though Mark had some health problems near the end of his life, he really did live each day and moment to the fullest. As Ms. Baker put it, "We are a more tolerant family, knowing that gifts come in all sizes, shapes, intellects. He left us a family in harmony, coming together to mourn and celebrate his life."

Ashley Coulter coordinates the Sibling Project at the Vanderbilt Kennedy Center and has a brother who has cerebral palsy.



INFORMATION SHEET ON RESTRAINT & SECLUSION

*Created by the Disability
Coalition on Education*



Although this tip sheet is not intended to specifically address students on the autism spectrum, many students with autism exhibit challenging behaviors which, too often, put them in jeopardy of being restrained or secluded in school settings. The editors of *Breaking Ground* felt it was important to provide this tip sheet in this, our special autism issue.

The Special Education Isolation and Restraint Modernization and Positive Behavioral Supports Act took effect in Tennessee on January 1, 2009. For the text of the law, go to <http://www.michie.com/tennessee/lpext.dll?f=templates&fn=main-h.htm&cp=tncode>; then select Title 49, Chapter 10, Part 13. This law is about the use of restraint and isolation in public schools.

Restraint means limiting a student's freedom of movement by physical contact or holding.

Isolation, sometimes called seclusion, means confining a student alone in a room or space from which the student is physically prevented from leaving.

"Time-out" in an area from which the student is NOT physically prevented from leaving is not considered to be isolation.

Schools CANNOT:

- restrain a child in any position that restricts breathing or is life-threatening, such as face down or putting weight on the chest;
- use mechanical restraint, such as straps, lap belts or ties;
- use chemical restraint, such as misuse of prescription medication to restrict a child's freedom of movement;
- use Mace, pepper spray or any other noxious (unpleasant) substance;
- lock a child in a room, closet or other confined space; and
- restrain or isolate a child as punishment, coercion, convenience or retaliation.

Schools MAY:

- use restraint or isolation in emergency situations; or
- use restraint or isolation if written into a child's Individualized Education Program (IEP).

Schools **MUST** notify a parent or guardian and call an IEP meeting:

- if restraint or isolation is used when not in the child's IEP; or
- if restraint or isolation is used for a longer time than what the child's IEP says.

The school **MUST** record the facts surrounding the use of isolation or restraint. If the parent or guardian asks for the record, the school **MUST** give it to them. However, the school is not required to give the record to the parent or guardian unless asked.

If your child has problems with behavior, the IEP team should write an individualized positive behavior intervention plan (BIP), based on a functional behavior assessment (FBA). Restraint or isolation should be a last resort, when there is danger of someone getting hurt.

If members of the IEP team suggest writing restraint or isolation into your child's IEP, you should:

- ask for information about the rights and protections your child and you have under Tennessee's restraint and isolation law;
- ask to see your school system's policies on restraint and isolation;
- ask what training the school staff have had;
- ask that the shortest time appropriate be applied;
- ask in what specific circumstances restraint or isolation would be used (such as risk of injury);
- ask to see the room used for isolation (sometimes called a "quiet" or "calming" room);
- ask to be notified every time your child is restrained or isolated;
- ask to bring the team back together, if your child is restrained or isolated frequently; and
- ask that all these points be put in writing in the Behavior Intervention Plan, the Crisis Intervention/Safety Plan, and the Prior Written Notice you should receive at the conclusion of every IEP meeting.

If you disagree with the proposed use of restraint or isolation, you can:

- ask that the team meet again to consider your objections;
- ask to talk with someone in your local special education office;
- ask that the school pay for an outside evaluation, if you disagree with a behavior assessment done by the school;
- talk to an advocate; and
- if these steps are not successful, you can file a request for a due process hearing.

In Tennessee, if you refuse to sign an IEP which the school system presents to you, the school can start using the IEP on the 15th day after you've refused, unless you file for due process.

If you believe that your child has been harmed by the use of restraint or isolation, you can:

- seek medical attention immediately;
- take photographs of any injuries;
- notify the school;
- contact the Disability Law & Advocacy Center (info below);
- if appropriate, make a report to Child Protective Services (toll-free: 1-877-237-0004); and
- if appropriate, make a police report.

For information or advocacy assistance, contact:

Disability Law & Advocacy Center of TN

Phone: 1-800-342-1660

TTY: 1-888-852-2852

Email: GetHelp@DLACTN.org

Tennessee Disability Coalition's Family Voices of Tennessee

Toll free family line: 1-888-643-7811

Email: familyvoices@tndisability.org

The Arc of Tennessee

Phone: 615-248-5878

Toll Free: 1-800-835-7077

Email: info@thearcn.org

STEP (Support and Training for Exceptional Parents)

Phone: 1-800-280-STEP

Espanol: 1-800-975-2919

TTY: 423-639-8802

Email: information@tnstep.org

Tennessee Disability Pathfinder

Phone: 1-800-640-4636

Web site: tnpathfinder@vanderbilt.edu

The Disability Coalition on Education, DCE, is a statewide alliance of families, agencies and advocacy organizations working together to improve educational outcomes for students with disabilities. If you want to learn more or to be added to DCE's mailing list, send an e-mail to hlu1055@comcast.net.

MULTICULTURAL PROGRAM AT TENNESSEE DISABILITY PATHFINDER AND VANDERBILT KENNEDY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

BY CAROLE MOORE-SLATER & ALEX SANTANA



Tennessee Disability Pathfinder, a statewide bilingual information and referral service for individuals with disabilities and program of the Vanderbilt Kennedy Center and the Tennessee Council on Developmental Disabilities, recently initiated a multicultural expansion to include all refugees and immigrants needing disability information and community services. Pathfinder's first

outreach efforts in the multicultural community began with the Hispanic Outreach Program in 2004. The success of this program, combined with the experience gained from working with families who speak Spanish, will assist Pathfinder staff as the program expands to include other immigrants and refugees with family members who have a disability.

As part of this expansion of Pathfinder's Multicultural Program, two refugees have been added to the staff so that families can receive services in their native language, but also to provide a better understanding of what refugees face having moved to this country. The new Multicultural Coordinator is Alexander Santana, a refugee from Cuba, who has lived in this country for two years. In addition, Aram Torabian arrived in Tennessee with his family from Iran over 10 years ago and speaks Kurdish, Farci and limited Arabic. Mr. Torabian is a student at Tennessee State University and works part-time with Pathfinder. Both staff members are well connected to the refugee community in Middle Tennessee, a launching point for creating a disability information source statewide.

"I still remember when I arrived to this country it was a big cultural shock for me," said Mr. Santana. "Despite all the support from the resettlement agency, it has been a difficult experience to navigate all the steps along the way when learning to live in a new country. I feel like I did not fully use all the community resources available for refugees. I cannot even imagine how hard it is to face the same situation and have a family member with a disability.

CONTINUED ON PAGE 14 →

"Now I am in a position where I can help to make this an easier process for individuals with disabilities, thanks to the existence of the Disability Pathfinder program here in Tennessee," continued Mr. Santana. "I am very grateful for the efforts the Vanderbilt Kennedy Center is making to work with families from different cultures."

Pathfinder is planning to work with other refugees and immigrants living in Tennessee who need information about disability services and community resources. It is important to realize that, although refugees and immigrants share commonalities, there also are significant differences. Common factors shared by refugees and immigrants when a family member has a disability include:

- Language barriers;
- Different cultural perspectives about disabilities;
- Access to disability services; what is available and how to obtain this information;
- Understanding of government procedures and regulations when completing applications; and
- Limited social support.

However, differences between refugees and immigrants play an important role when considering health, disability and community social services.

Refugees are individuals who are forced to leave their countries because of war, political persecution or environmental disasters. They are invited to live in the United States and have special immigration status, short-term health insurance benefits, short-term financial aid, and a work permit. All refugees are processed through a refugee resettlement program and have case managers who assist with obtaining Social Security numbers, securing housing, clothing and food, medical screenings and immunizations, finding English as a Second Language (ESL) classes for adults and helping families enroll children in school. The goal is for refugees to become self-sufficient and integrated into the community. Refugees are followed by case managers for a specified time period.

Immigrants generally come to the United States to join family members who already live in this country or to seek work and a better life for their family. Immigrants often have family support but do not have access to services available to refugees. Accessing health, disability and social services is often difficult.

Understanding differences between immigrants and refugees provides important information, not only as Pathfinder works to identify available multicultural resources, but also in planning effective strategies and collaborations with other agencies.

Pathfinder's philosophy is to teach families or individuals with disabilities what services are available and how to access systems when seeking specific services. Previous experience has taught us that communication is a barrier to receiving services, whether it is language

related or lack of awareness about existing community services available to offer assistance.

For this reason, Pathfinder has focused on networking in the community with agencies or individuals working specifically with refugees and immigrants. This has included attending community meetings and conferences, volunteering for planning meetings at resettlement centers, and building relationships with staff and volunteers. As Pathfinder establishes relationships with anchor agencies serving refugees and immigrants, we are learning there are gaps in information provided regarding disability services. Pathfinder is planning to work collaboratively with these programs.

Although the Multicultural Program expansion with Disability Pathfinder and the Kennedy Center is evolving, we have identified the following goals for 2010-2011.

1. Work with immigrants and refugees, speaking any language, seeking disability information or services. Vanderbilt interpreter services will be used as needed.
2. Network with staff at agencies serving refugees and immigrants to identify community resources, interpreters and families needing disability services.
3. Expand Pathfinder's statewide agency database to include "multicultural resources" in addition to "bilingual providers".
4. Collaborate with other agencies serving refugees and immigrants to provide disability-related information or work jointly to create programs, like support groups, in the community.
5. Provide cultural diversity training and presentations across the State.
6. Serve as a liaison between non-English speaking individuals and various clinics, programs and research opportunities at the Vanderbilt University Kennedy Center in Nashville.

For further information, please contact the following Multicultural staff in the Pathfinder office:

Alexander Santana, *Program Coordinator*

615-875-5083

alexander.santana@vanderbilt.edu

Carolina Meyerson, *Spanish Services Coordinator*

615-400-4422

carolina.meyerson@vanderbilt.edu

Cecilia Melo-Romie, *Statewide Outreach Coordinator*

615-479-9568

cecilia.melo-romie@vanderbilt.edu

Aram Torabian, *Kurdish Outreach Case Manager*

615-875-5083

aram.torabian@vanderbilt.edu

Carole Moore-Slater is the director of Tennessee Disability Pathfinder.

C is RED



BY EMELYNE BINGHAM

C is red. I don't know why. Perhaps it's because the C on my childhood toy xylophone was red, or maybe because somewhere along the line I heard someone mention the "Red Sea (C?)", or maybe it just sounds red in the same way that G sounds blue, D sounds yellow, E black, and so on. Whatever the case, the multi-sensory experience—or synesthesia—I had while lying under our grand piano for hours as my mother practiced took precedence early on, far eclipsing a preference for toys and television-watching that most two year olds possess.

I'm sure that was but one of the many things my parents saw letting them know that their little girl was a little bit different. I was potty-trained at 11 months and speaking full sentences by the age of two, even though I suffered from selective mutism and still do today. I also could read books and play Beethoven sonatas by ear at three (as much as a three-year-old's hands can reach). Wonderfully precocious as that may sound, things were far from easy. Autism in the 1960s wasn't exactly on the average person's radar, and my parents, like many others, had absolutely no clue what to do.

I don't remember much about those very early years, or even my first few years of school. Much of what I now know was revealed in some documents I discovered following my mother's death. What I do remember was being bounced around from classroom to classroom: up a grade, up two grades or even three grades, back down to my original class in, what is now obvious to me, an attempt to match and balance my social and academic needs. I remember well the sense of failure I felt when I knew something was very different about me. And the phone calls. How I remember my mother seemingly forever on the phone with my teachers, usually in tears. Thankfully, piano studies provided the much-needed consistency I craved.

Music studies at age eight were interrupted when my family left Chicago for Tennessee. The isolation and disruption I felt following the move led me to experience music even more deeply. Soon thereafter, I discovered a set of recordings—the nine symphonies of Beethoven. These recordings brought my interest, and my synesthesia, to a whole new level. I became fascinated with the symphony orchestra, especially the big double bass and that mysterious art of conducting. Somewhere between the recordings and the radio and perfect pitch and those Saturday night broadcasts of "Evening at Pops" with Arthur Fiedler on public television, I felt like I could play the bass. No, I knew I could play the bass because I had already figured out the fingering system and how it was tuned.

Although my interest in classical music never waned, opportunities for study did, and so my passion and nascent talent lay dormant until my sophomore year of college. Adjustments to academic and student life in college can be difficult for many undergraduate students, but they can

be incredibly overwhelming to someone on the autism spectrum. My situation, unfortunately, was no different. Navigating a new social scene and an unfamiliar academic routine had taken a toll on my anxiety level, and my grade-point average.

I remember leaving my physics class one afternoon realizing that college was not going to be a possibility for me. As I walked past the music building on campus, I could hear the faint sounds of an orchestra rehearsing. Immediately my curiosity took hold and I spent the next hour leaning through the open window, fascinated by what I saw and heard. Afterwards, the conductor tracked me down to find out why in the world I stood outside for an entire hour just to listen to a rehearsal. Six months later, I was still in school, had a full music scholarship and a part-time job playing bass in the Knoxville Symphony Orchestra.

I was fortunate. I had a group of professors who were excellent teachers and intuitively knew how to present material in ways I could understand. They also knew that the classical music world was no exception when it came to the importance of good social skills, so they took me under their collective wings and taught me some basic things, like how to look people in the eye and introduce myself. This dedication to "teaching the whole student" has become a core component of my own teaching philosophy.

Undergraduate school turned into graduate school. Over time, I became less interested in playing bass. There just wasn't enough to occupy my overly active mind and I felt my creativity stifled sitting in the back of the orchestra. I began to study scores voraciously, partly to hold my interest and partly to prepare me for the sudden loud passages that jolted my hypersensitivity to sound. Most importantly though, to me, music has always felt inextricably entwined with movement. My fascination with gesture combined with the in-depth score study that fueled my synesthesia and kept me out of trouble in the back of the orchestra naturally led to conducting. And, thankfully, despite those challenges past, present and yet to come, I've been able to make a fulfilling career.

Is it really that unusual for an individual with autism to be musically gifted? There is evidence to suggest that people with autism process musical concepts differently than the neuro-typical population. Studies also show that persons on the autism spectrum perform some low-level musical processing tasks more accurately than non-Autism Spectrum Disorder controls, and that the idea of global-processing deficits in the auditory and visual modalities in individuals with autism is seriously questioned. (For example, see the paper "Local and Global Processing of Music in High-functioning Persons with Autism: Beyond Central Coherence?" by L. Mottron, I. Peretz and E. Ménard in *Journal of Child Psychology and Psychiatry*, 2000, 41, pp 1057-1065.)

Am I all that unusual as a musician with autism? I don't know. I do know that it takes a village to rear any child, especially one on the spectrum. I know that we have a long way to go when it comes to accepting individuals on the spectrum to fully integrate them into all aspects of life and work. I know that despite the difficulties I have been incredibly fortunate. And, most importantly, I know that C is red.

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Emelyne Bingham is senior lecturer of Aural Studies at the Blair School of Music, Vanderbilt University.

TENNESSEE AUTISM SUMMIT TEAM

BY COURTNEY TAYLOR

With the goal of developing a comprehensive State plan to improve autism identification and service systems, the Vanderbilt Kennedy Center and the University of Tennessee Boling Center for Developmental Disabilities host a team of key State leaders for the national Autism Summit Project. The team includes parents of children with autism spectrum disorder (ASD) and members of autism advocacy organizations; representatives of State departments of education, health, intellectual and developmental disabilities, and social services; and university-based professionals from diverse disciplines. The Governor's Office on Children's Care Coordination and the Comptroller's Office are also active partners.

"The Autism Summit provides an exciting opportunity to come together with key stakeholders in Tennessee to share, discuss and learn from each other," said Terri Urbano, PhD, MPH, RN, Director of Vanderbilt's Leadership Education in Neurodevelopmental Disabilities (LEND) program. "It is exciting to see how our efforts have served as catalysts for collaborations between organizations working to improve and enhance early identification and intervention efforts for children and families with autism spectrum disorder and related disabilities."

The Tennessee team meets quarterly and has established four priority areas: supporting family participation in the improvement and expansion of the ASD service system; promoting statewide public awareness by disseminating the CDC's (Centers for Disease Control and Prevention) "Learn the Signs. Act Early" campaign materials; training pre-service and community professionals and parents/families; and coordinating the Autism Summit with statewide activities.

FAMILY PARTICIPATION

"This is the first time in almost a dozen years as a parent and advocate that I can remember having such a gathering of key decision-makers in one place, with a singular focus on the question of how we can 'advance the ball' for autism clinical and diagnostic services across Tennessee for children with or at risk for an autism spectrum disorder," said John Shouse, a parent and Board member of the Autism Society of Middle Tennessee. "It is important that we see so many family members involved on the team. As we work to improve the service system, I think it is especially important that the voices of families are included in the conversation."

To support family participation in improving the ASD service system, the Tennessee Team applied for and was the recipient of an Autism Summit Mini-Grant offered by the Association of University Centers on Disabilities. This additional funding continues to support travel and related needs of Autism Society of America (ASA) chapter Team members across the State to ensure ongoing participation of family members in all aspects of the project. The mini-grant also allows for the dissemination—through TEIS (Tennessee Early Intervention



System) and local ASA chapters—of information about ASD, including locally-specific orientation and resource guides for families of children newly diagnosed with ASD. To view the family resource guides, see: kc.vanderbilt.edu/autismresources.

PUBLIC AWARENESS

In addition to disseminating local resource guides to Tennessee families, Summit Team members have focused efforts on disseminating the CDC's "Learn the Signs. Act Early" campaign materials. The campaign offers free resources about child development in English and Spanish. The purpose of the materials is to educate parents, educators and health care professionals about developmental milestones and warning signs of a development delay such as autism, and the importance of acting early to obtain screening, diagnostic and intervention services.

The campaign also provides print, radio and television public service announcements (PSAs) in English and Spanish. Team members have worked successfully with local Hispanic newspapers and radio stations willing to run the PSAs. To access and run the PSAs or to order the free CDC materials, visit: www.cdc.gov/actearly.

TRAINING

The Autism Summit has served as a catalyst for collaborations between agencies with training efforts in the area of ASD. Vanderbilt Kennedy TRIAD (Treatment and Research Institute for Autism Spectrum Disorders), the Vanderbilt LEND program and the UT Boling Center have partnered to expand STAT-MD Training. This training prepares pediatric medical providers to conduct enhanced diagnostic consultation and screening procedures. This partnership has allowed the Middle Tennessee workshop-based trainings to expand to both the eastern and western portions of the State. The goal is to develop a statewide network of pediatricians capable of identifying autism concerns and initiating appropriate early intervention services without prolonged waits.

Another training collaboration made possible through Autism Summit activities is a partnership between TEIS and the Autism Society of Middle Tennessee (ASMT). TEIS funded the expansion of ASMT's Autism Orientations to East and West Tennessee. This will allow more families to benefit from the informational sessions on autism and other

pervasive developmental disorders that are conducted by an autism specialist and a parent of a child with autism.

COORDINATING THE AUTISM SUMMIT WITH STATEWIDE ACTIVITIES

The Autism Summit serves as a venue for communication and discussion of community agency activities in the area of autism. Recently, the Team was presented with the second in a series of three reports developed by the Comptroller of the Treasury's Offices of Research and Education Accountability that examine public services for infants, children and youth with autism in Tennessee. [See Studying Autism Services in Tennessee on page 8 of this issue.]

"Autism in Tennessee: Part 1 – An Introduction to Issues and Data Collection Methods" provides an overview of autism as a disability, a review of associated laws, and includes autism data collection and prevalence estimates. "Autism in Tennessee: Part 2 – Education" focuses on public education services for students with autism. The third report will explore health care services as they relate to autism in Tennessee. To view these reports, search the "publications" section of

the Tennessee Comptroller of the Treasury's Web site at: www.comptroller1.state.tn.us/index.asp.

Next on the agenda for the Autism Summit is to hold a series of conversations about what it might take to update the "Autism Services Proposal for the Tennessee Legislature", which was written in 2002. To view the Proposal, visit: http://kc.vanderbilt.edu/kennedy_files/AutismServicesProposal12-23-2002.pdf

Regional summits are jointly sponsored by the National Center for Birth Defects and Developmental Disabilities of the CDC and the Maternal and Child Health Bureau at Health Resources and Services Administration, and facilitated by the Association of University Centers on Disabilities.

For information on the Act Early Regional Summits, see the Summit's link at www.aucd.org. For information about the Tennessee Act Early Team, contact jan.rosemergy@vanderbilt.edu, 615- 322-8238.

Courtney Taylor is associate director of Communications and Dissemination at the Vanderbilt Kennedy Center.

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www.tndisabilitymegaconference.org

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BY ANGELA BECHTEL

As the population of individuals with autism continues to increase, the demand for resources to support them, their families and caregivers continues to rise as well. The scope of needs is broad and includes evaluation and diagnosis, traditional and alternative therapies, recreational activities, educational advocacy, postsecondary transition resources and support for families.

When looking for resources, it is often helpful to contact advocacy organizations or comprehensive facilities that serve specific disabilities. The following agencies serve as "gateways" to a wealth of useful information relevant to autism; in addition, they often provide opportunities to network with individuals and families, which can be helpful too.

Autism Society of East Tennessee (ASA-ETC)

Brook Dickerson
865-247-5082 • asaetc@gmail.com

Autism Society of Middle Tennessee

Amanda Peltz
866-508-4987, Toll Free • 615-385-2077 • asmt@tnautism.org

Autism Society of the Mid-South

Kate McDonald
901-542-2767 • autismsocietymidsouth@yahoo.com

Autism Engagement Center

Dr. Aimee Lyst
615-550-3570 • autismengagement@gmail.com

Autism Solution Center Foundation, Inc.

Laura Corby
901-758-8288 • info@autismsolutioncenter.com

UT Boling Center for Developmental Disabilities

Frederick Palmer, MD
888-572-2249, Toll Free • 901-448-4677, TTY
901-448-6511 • fpalmer@uthsc.edu

The Pathfinder Web site has a searchable database of autism resources that can be accessed at www.familypathfinder.org. To search, go to "Services Database", enter the type of resource you need under "Service Category" and where you need it under "Geographic Location" and you will generate a list of resources. For example, service category "respite care services" and geographic location "Shelby County" produces the following six agencies that provide short-term care for children and adults with disabilities.

The Arc of the Mid South

Carlene Leaper
901-327-2473 • cileaper@arcmidsouth.net

Easter Seals of Tennessee

Mary Gardner
615-385-3485, TTY • 615-292-6640 • mgardner@eastersealstn.com

Elder Care Home Health Services

Shearlean Dowell
901-398-2167 • shearlean.dowell@eldercareservicesinc.net

Ryan's Ranch International

Corinne Derenburger
901-861-7039 • info@ryansranch.org

Support Solutions of Mid-South, LLC

Larry Durbin, EdD
901-383-9193 • sdurbin@supportsolutionsms.com

Tennessee Respite Coalition

Jennifer Abernathy
888-579-3754, Toll Free
615-269-8687 • jennifer.abernathy@tnrespit.org

Other categories of autism-relevant resources on the Pathfinder Web site include behavioral services, camp information, employment services/vocational training, Family Support Program, horseback riding therapy, IDEA information or training, residential services, support groups, therapy clinics and transportation services. In addition, you will find two "Autism Parent Guide"s, as well as a "Tennessee Autism Resource List 2010" under "Pathfinder Flyers and Materials".

Don't have Internet access? You can still access Pathfinder's resources easily by simply dialing the Helpline at 1-800-640-4636 or 615-322-8529. Our staff is ready and waiting to help you locate the information you need about autism-related and other resources related to disabilities.

FREE DOWNLOAD!

STATEWIDE DISABILITY SERVICES DIRECTORY AVAILABLE

Tennessee Disability Pathfinder is pleased to announce the release of the new, printable **2010-11 Disability Services and Supports Directory**, available for download, free of charge.

- Includes information on over 1,800 agencies throughout Tennessee that provide more than 4,000 programs for individuals with disabilities.
- Divided into sections for easier navigation and more flexible printing options.

Angela Bechtel, MSSW, is information & referral services coordinator with Tennessee Disability Pathfinder.

FOR FURTHER INFORMATION Tennessee Disability Pathfinder

English & Español
(615) 322-8529
(800) 640-4636

TTY/TDD users:
please dial 711 for
free relay service

www.familypathfinder.org
tnpathfinder@vanderbilt.edu

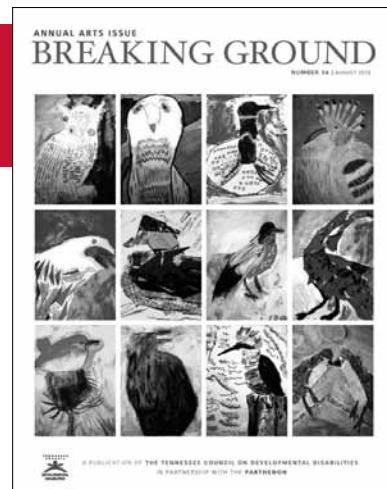
Tennessee Disability Pathfinder has phone, Web and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers and advocates. Pathfinder is a joint project of the **TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES** and the **VANDERBILT KENNEDY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES**.

INVITING YOU TO CONTRIBUTE TO OUR SPECIAL ANNUAL ISSUE OF *BREAKING GROUND* DEVOTED TO THE ARTS

Do you write short stories or poetry?
Do you paint, draw or take pictures?
Then we'd like to see your work for possible publication!

THE EDITOR WILL CONSIDER:

- fiction, up to 1,000 words, and poems, whether traditional or modern.
- photos and all other forms of artwork.



ALL ENTRIES MUST BE SUBMITTED BY JUNE 15, 2011

Content is devoted to materials by or about persons with disabilities.

We'll give contributors a prominent by-line,
a biographical note and copies of the issue.

Please include your name, complete contact
information and a two- or three-sentence
biography with your submission.

SEND YOUR SUBMISSIONS TO:

Ned Andrew Solomon /Managing Editor, *Breaking Ground*
Tennessee Council on Developmental Disabilities
Parkway Towers, Suite 130 • 404 James Robertson Parkway
Nashville, Tennessee 37243-0228 • ned.solomon@tn.gov

Questions? call 615-532-6556



The Council on Developmental Disabilities is seeking applicants for its

2011-12 PARTNERS IN POLICYMAKING LEADERSHIP INSTITUTE

What is the Partners in Policymaking Leadership Institute?

Partners in Policymaking is a free leadership and advocacy training program for adults with disabilities and family members of persons with disabilities, funded by the Tennessee Council on Developmental Disabilities. The Partners program has been training Tennesseans since 1993.

What will Partners learn?

Over the course of seven, once-a-month weekend sessions (from 12 pm on Friday through 3 pm on Saturday), Partners will attend workshops conducted by national and local experts, on:

- The History of the Disability Experience
- People First Language
- Best Practices in Inclusive Education
- Building Inclusive Communities
- Self-Determination, Self-Direction and Person-Centered Practices
- Assistive Technology
- Supported & Independent Living in the Community
- The State and Federal Legislative Processes
- Employment Strategies for Persons with Disabilities
- Conducting Effective Meetings

Partners also will tour the Capitol, meet with a Tennessee Legislator, and participate in a Mock Testimony designed to enhance their public policy advocacy skills. In February, all Partners graduates since 1993 are invited to attend an annual reunion conference, with keynote speakers and breakout sessions on a variety of topics.

The seven weekend sessions take place September through November, and January through April.

Where does Partners take place?

Partners sessions take place at a hotel in Middle Tennessee. All participants are required to spend the night and attend all seven sessions. There is no cost for hotel rooms or meals during the program times and the trainings, or mileage to and from each session.

What is the deadline to apply for the 2011-12 Partners season?

All applications must be postmarked by **APRIL 30, 2011**.

How do I apply or get more information?

If you need an application sent by mail or e-mail, or have any questions about the program, including eligibility, please contact program director Ned Andrew Solomon at 615-532-6556, or by e-mail at ned.solomon@tn.gov.

VANDERBILT UNIVERSITY

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